

# Caregiver Perceptions of Wichita State University's Autism Interdisciplinary Diagnostic Team Process

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**Abstract.** The purpose of this pilot study was to obtain perceptions of caregivers' experiences after participating in Wichita State University's Autism Interdisciplinary Diagnostic Team (AIDT) process. Interviews were conducted in participants' homes and on-campus. Each interview was digitally recorded and transcribed. Data were analyzed using grounded theory qualitative analysis to identify common themes across participants and conceptualize families' experiences of the process. Common themes identified from initial interviews included benefits of simultaneous assessment of children's abilities by multiple disciplines, professional validation of parent concerns, expedited medical diagnostic processes and enrollment in early intervention services, need for follow-up counseling for parents and families, and increased levels of hope for children's future endeavors and overall well-being. Future directions for research include further interviews to reach saturation of common themes, which would enable researchers to establish a model conceptualizing caregivers' experiences of participation in an AIDT process.

## 1. Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that can cause significant social, communication, and behavioral challenges (CDC, 2014). Given the pervasive nature of ASD, multiple areas of functioning can be affected (e.g., fine- and gross-motor skills, communication, speech, language, hearing, executive functioning, psychosocial functioning, acquisition of academic and vocational skills, and relationship development), which can make diagnosing ASD a lengthy, difficult process. Wichita State University's Autism Interdisciplinary Diagnostic Team (AIDT) includes students and faculty from speech-language pathology, audiology, physical therapy, clinical psychology, early childhood education, dental hygiene, and nursing; as well as community partners from the University of Kansas School of Medicine - Wichita (represented by a developmental pediatrician and an Advanced Practice Registered Nurse). The disciplines collaborated to provide interprofessional diagnostic services for children who have been brought to the team by their parents/caregivers who have expressed concern for their child's development.

Interdisciplinary teams are recommended for an accurate, comprehensive diagnosis of ASD (Myers & Johnson, 2007; Prelock, 2006), and caregivers (e.g., parents, grandparents, etc.) play a pivotal role in this process by providing personal insights into and observations of their child's personality, behaviors, strengths, and challenges. There is a dearth in the literature regarding caregivers' perceptions of their family's experiences with interdisciplinary autism diagnostic teams. Thus, this research explored the experiences of caregivers' perceptions with WSU's AIDT with the aims of understanding the family's perspective of the diagnostic process, improving the process to better meet families' needs, and contributing to the literature in support of other institutions providing or considering providing similar services to families in need.

## 2. Experiment, Results, Discussion, and Significance

### *Participants*

Participants for this study included three caregivers of children assessed by the AIDT. Following approval of the study by WSU's Institutional Review Board, the caregivers were contacted and asked if they would be willing to meet with a trained graduate student from the department of Communication Sciences and Disorders to discuss their experience with the AIDT. Informed consent was discussed and presented in writing to each participant.

### *Experiment*

After consenting, the caregiver(s) engaged in a digitally recorded, 45-60 minute, semi-structured dialogue with the graduate student regarding their experience with AIDT. A series of open-ended questions designed to facilitate sharing experiences the caregivers felt were most important about the AIDT process were asked during the discussion. Additional topics of importance to the participants, though not always targeted in the prepared questions,

were discussed to the extent the participants felt necessary.

Dialogues were digitally recorded using a Marantz® PMD670 Solid State recorder and a Shure Centravert™ Boundary Condenser external microphone. A trained graduate student researcher transcribed the recordings, and two trained graduate student researchers analyzed the transcriptions in the open and axial coding processes. These processes entailed identifying all themes presented in each transcribed dialogue, then identifying themes shared by multiple participants from the transcriptions. Researchers compared their coding results, and inter-rater reliability was established at 98% agreement.

### Results

Prevalent themes from discussions that emerged during data analysis included:

- (a) caregivers appreciated the interdisciplinary approach to assessing their child,
- (b) caregivers' concerns were validated by the AIDT professionals,
- (c) medical diagnostic processes were expedited,
- (d) the need for follow-up counseling for parents and siblings was identified, and
- (e) caregivers felt hopeful regarding their children's future endeavors, potential autonomy, and overall well-being.

### Discussion

The nature of qualitative methodology employed in this research allowed researchers to pursue topics of the AIDT experience that were significant to the caregiver(s). The flexibility of this design facilitated the emergence of aforementioned prevalent themes. Many caregivers felt their isolated, one-on-one experiences with multiple professionals prior to their experience with AIDT resulted in fragmented, incomplete conceptualizations of their child. As the presentation of symptoms of ASD and their severity can vary contextually (American Psychiatric Association, 2013; Janzen, 2003), a comprehensive understanding of a child from the vantage points of multiple disciplines at one time can greatly benefit the diagnostic process. It seems that many caregivers felt the AIDT provided such a comprehensive, 'complete,' view of their children.

Some caregivers struggled with other professionals, and sometimes spouses, who doubted their concerns about their child's development. It seems that,

regardless whether their child received a diagnosis, caregivers felt their concerns were received, validated, and addressed by the AIDT. Participating with the AIDT expedited the process of attaining a medical diagnosis for many families, which subsequently allowed them to enroll their child in critical early intervention services. All interviewed caregivers shared feeling increased levels of hope for their children's future endeavors, potential autonomy, and overall well-being.

### 3. Conclusions

Interdisciplinary diagnostic assessments are highly recommended for children who may have ASD. Caregivers provide invaluable information during such assessments. This study has revealed multiple themes of caregivers' perceptions from their participation in an interdisciplinary ASD diagnostic process. The AIDT process validated caregiver concerns and established diagnostic profiles caregivers felt best represented their children. Follow-up counseling interventions for caregivers and family members may help them work through emotional and psychological challenges they may experience as a result of the diagnostic process.

Future research in this area should include further interviews to reach saturation of common themes, which would enable researchers to establish a model conceptualizing caregivers' experiences of participation in an AIDT process. Additionally, it may be worthwhile to investigate how parents view their child before and after receiving a diagnosis of ASD, and how their interactions with their child may shift as a result of receiving a diagnosis of ASD. Work in these areas would further explicate researchers' and service providers' understanding of dynamics of families with children with ASD and enhance the quality of family-centered interventions and service provision to these families.

### 4. References

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